NEWSLETTER

HUNTINGTONS QUEENSLAND

July 2011

CONTENTS

FROM THE PRESIDENT

Dear Friends

It was mentioned in our May Newsletter that the Association has been awarded a grant from the Department of Communities (Disability Services) to acquire equipment and aids that will improve the quality of life of those suffering from HD and their families. I am pleased to advise that we have now received this grant and we have held our first session to plan its operation. It will be known as 'HQ Assist'. We will be providing more information over the next few months.

As another financial year closes we will be holding our Annual General Meeting prior to the end of September and have decided to conduct the AGM in conjunction with a dinner to celebrate the 35th anniversary of our Association. This will be held at the Sunnybank Community and Sports Club on Thursday 22nd of September 2011. There are more details later in the Newsletter.

I would like to welcome two new members to the Management Committee, namely, Keryn Stewart and Esther Elliott. With the AGM coming up I would like you all to consider joining the Committee. It is always good to have new people and new ideas to help in taking Huntingtons Queensland forward.

For those members not already paid, I invite you all to pay your annual Association renewal fee for the 2011 – 2012 year. Please complete and return the enclosed renewal form. Annual membership fees are an important part of our income stream but I'm very glad to report that we have been able to maintain our fees at $30 for families and $20 for single memberships. We would also welcome any new members who may be interested in becoming part of Huntingtons Queensland.

All the best!

Gerry Doyle, President

DIARY DATES

August 2011

1st August	Sunshine Coast Family Support Group (Lesley)
2nd August	Coffee catch up – Caboolture/Pine Rivers Peninsula & Brisbane North (Tressa)
8th – 12th August	Townsville regional visit (Lesley)
24th August	Eastern Suburbs Satellite Respite Group (Tressa)
29th August	Gladstone/Rockhampton regional day visit (Tressa)
31st August	Gold Coast Family Support Group (Lesley)

September 2011

1st September	Pine Rivers Peninsula Family Support Group (Lesley)
11th – 14th September	World Congress on HD in Melbourne
21st September	Eastern Suburbs Satellite Respite Group (Tressa)
22nd September	AGM / 35th Anniversary Dinner
26th September	Brisbane Carers Support Group
28th September	School holiday activity
30th September	Toowoomba Family Support Group (Christine Fox nee Parfait)

October 2011

4th October	Coffee catch up – Caboolture/Pine Rivers Peninsula & Brisbane North (Tressa)
5th October	Burnett regional day visit (visiting Welfare Officer to be advised)
12th October	Gold Coast Family Support Group (Lesley)
17th October	Sunshine Coast Family Support Group (Lesley)
19th October	Eastern Suburbs Satellite Respite Group (Tressa)
24th – 28th October	Cairns regional trip (Lesley)
26th October	Brisbane Carers Support Group

FROM THE OPERATIONS MANAGER

Greetings all! The year is progressing well, if at an ever increasing pace. They say that the reason each year seems to go faster than the previous is as follows. When you are two years old, a year is fifty per cent of your entire life. When you are twenty, a year is five per cent of your life so far. When you are fifty, a year is two per cent of your life. And that makes it seem that time is going faster. But on the other hand there are still the same number of clock ticks in each year, so it must all be relative and about perceptions. Anyway as they say time flies when you are having fun.

On the subject of time passing, Huntingtons Queensland celebrates its 35th Anniversary this year. That is a great milestone, and when I see the support work being provided by our welfare team on a daily basis, including day respite activities, support group meetings, holidays and outings for children of people affected by Huntingtons, individual emotional support and provision of information sessions; when I see our involvement at the monthly HD clinic at the Royal Brisbane Hospital, a clinic which is of world standard; and when I receive a receipt and thank you letter from the University of Queensland in response to our donation of $25,000 towards the Huntingtons Research Scholarship Project, one of a series of such donations; when I see each of these things and so many more, and when I see the attitudes of the general members, the staff, the committee members, the families and the volunteers, I can say with great confidence that Huntingtons Queensland is doing a great job and that it is an organisation that can stand proud. I believe the greatest statement that we make, as we offer what support we can, and continue the 'hunt for the final cure', is that for those affected by Huntington's Disease, you don't stand alone.

We are celebrating our 35th Anniversary with a dinner at Sunnybank Community and Sports Club on Thursday 22nd September. The cost of the dinner is $35 per person. The dinner is for 7:30pm, but we will be having our Annual General Meeting at the same place commencing at 6:00pm. I invite and encourage you all to attend either or both of these events. It would be greatly appreciated if you could contact the office if you can attend, so that we can make suitable catering arrangements.

Also on the subject of time passing, and changes occurring, The Rotary Club of Acacia Ridge is closing. This club has had a long and supportive relationship with Huntingtons Queensland. Because of their support, we are able to provide financial support to children affected by Huntington's Disease, with the Acacia Ridge Rotary Scholarship. Gerry Doyle and I attended their final meeting and we were, on behalf of Huntingtons Queensland, the recipients of a further donation of $4,000 from Acacia Ridge Rotary Club. Great work Rotary and thank you very much. Barb Gray was unable to attend this meeting as she and Don were off travelling and enjoying themselves somewhere. Don't they deserve it? So upon the happy travellers return, the Rotary Club held a special 'final' final dinner to honour and thank Barb. At this dinner they presented Barb with the prestigious 'Paul Harris Fellow' award. This is a great honour and a highly regarded Rotary award. Congratulations Barb.

I would like to welcome and introduce two new committee members to you. **Esther Elliott** is a Genetic Scientist as well as being a Genetic Counsellor. Esther recently addressed our Brisbane Carers Support Group Meeting, and her address was well received and appreciated. Esther is representing us by attendance at the Human Genetic Society of Australasia, four-year conference, at the Gold Coast. We are fortunate to have such access to the latest in genetics research and knowledge.

Keryn Stewart has personal experience of HD through family members. Keryn has offered her services as swimming instructor for the children of families affected by HD. Keryn has a particular interest in helping children affected by Huntington's. She is involved with the Respite Day programme as a volunteer and the energy and enthusiasm that she brings to our cause is most welcome.

Gerry, Cliff and Jenny Farmer, Christine, Tressa, Lesley and I will be attending the Huntington's Disease World Congress in Melbourne in September. We look forward to the opportunities for networking and for familiarising ourselves with the latest developments relating to HD from around the world. I will report on this in a later newsletter.

I am developing a little mantra *'Huntingtons – continue the hunt (for the final cure)'*.

It's great to be a part of the team.

Michael McLean, Operations Manager

WELFARE NEWS

Hello friends and families. As I sit here to write to you all today from my office I am finding it hard to believe that I've been away for six months. It truly feels like a case of "blink and you'll miss it"! Has it been THAT long? And then I remember all those sleepless nights with a newborn, the days of not getting any housework done because the baby cries if you put her down, or wakes if you cough a little loud and then I think - has it ONLY been six months? I am happy now, though, to be back at work and look forward to catching up with families and service providers over the coming months. In the meantime though, feel free to give me a call or send me an email (christine@huntingtonsqld.com) to let me know how you are travelling. Initially, I'll be working a three day week, Tuesday, Wednesday and Friday, with the view to working four days a week by the end of the year.

There have been some exciting developments and events over the past few months as well. The **HD Buzz website** (www.hdbuzz.net) launched and what a fantastic resource this is. This site has some great information about what is going on in the world of HD and they are excellent at producing articles and re-writing findings of research projects to make them easier to understand. This month we've included an article on *Caffeine, Cannabis and Caution* from the website, and each newsletter we will continue to include articles that we think will benefit our HD community. Another good website that has undergone an upgrade is http://hopes.stanford.edu. "HOPES is a student-run project at Stanford University dedicated to making scientific information about HD more readily accessible to patients and the public" and it is a site that I regularly recommend for information to our families. Both these sites have a facebook page.

Our young families group is growing with each event that we hold – and why wouldn't it when last school holidays our families had a free day at Dreamworld! In all there were eight families who came along, 19 kids (aged from 5 to 17) with their parents. The older kids showed bravado and tackled the "upside down, throw 'em around and spin till you turn blue" rides and Tiger Island was a big hit. I hear the day was a great success and we were only too happy to be able to host this event with the assistance of Dreamworld and the Carer Respite and Carelink Centres, whom we would like to thank very much. If you or your family member are affected by HD and you have children that you think might like to join in on our school holiday events, or you'd like more information about this initiative, please feel free to give us a call and we can tell you more.

I was also excited to learn about a new initiative providing financial support to people trying to have an HD free baby from www.pgdassistance.com. In the last newsletter we included some information about this initiative, along with an article about reproductive options in response to information requests from family members, so keep those requests coming and we will try our best to see what we can source for you.

Then of course, the two big events here were the introduction of our new Operations Manager, Mike McLean, who has joined our team so seamlessly – it's great to have him on board. Secondly, the HQ Assist initiative we are setting up to provide medical equipment to people affected by HD. HD Assist is funded by the Queensland Department of Communities (Disability Services) and we would like to acknowledge their valuable contribution to our services. It's an exciting programme and we are now planning for its implementation and roll out in the coming months.

I'd like to finish off by offering a very big thank you to Theressa and Lesley who, whilst I was on maternity leave, took on the extra workload of my position along with their own. I can't thank them enough for their support and dedication to my clients over the past six months and I hope that they can now take a breath and slow down a little – although we don't really get much of a chance to do that around here and we wouldn't want it any other way. Not to forget Anne, Helen and Mike who have also gone above and beyond their roles to help our families – thank you. Take care everyone.

Christine Fox (going by my married name now), Senior welfare Officer

INFORMATION FOR CARERS

Carer Business Discount Card

The Carer Business Discount Card scheme recognises the significant contribution carers make to the lives of people they care for and the communities in which they live.

The card provides direct, real benefits to carers in acknowledgement of this contribution. When making purchases from registered businesses, simply present your Carer Business Discount Card to receive the discount or other offer.

To be eligible for a Carer Business Discount Card you must:

- be a resident of Queensland with a Queensland residential address registered with Centrelink, and
- receive the Centrelink Carer Payment or Carer Allowance.

For more details about the Carer Payment or Carer Allowance please contact Centrelink on 13 27 17 or visit the website www.centrelink.gov.au

Certainty for Queensland Disability Parking Permit Holders

15/03/2011 Joint Media Release with Annastacia Palaszczuk MP, Queensland Minister for Transport

All Queenslanders with a disability parking permit will now be able to access local disability parking concessions across Australia. This means that Queensland's 100,000 red permit holders, who have reduced mobility, can still access their red disability parking permit parking concessions when they travel interstate.

The Federal Parliamentary Secretary for Disabilities and Carers, Senator Jan McLucas, said the announcement is an important outcome for Queenslanders with reduced mobility. "Queenslanders with a red permit now have certainty and confidence when driving interstate." "Disability parking concessions help make life easier for people with reduced mobility to stay connected with their community, reducing walking distances and anxiety when heading to work, visiting the doctor or going shopping."

The Queensland Minister for Transport, Annastacia Palaszczuk, said the recognition of red permits across Australia would be welcome news to many Queenslanders, particularly those living near New South Wales who may drive regularly across the border. "We'll now have a disability parking permit system that does not recognise borders making it easier for the disabled and those administering the system," Ms Palaszczuk said.

All disability parking permit holders should check the local rules for parking and obey all other road and parking conditions. Further information about the Australian Disability Parking Scheme and links to each state and territory disability parking agency are available at www.disabilityparking.gov.au

SCAMwatch is a website run by the Australian Competition and Consumer Commission (ACCC) and provides information to consumers and small businesses about how to recognise, avoid and report scams. Many scams originate overseas or take place over the internet, making them very difficult to track down and prosecute. If you lose money to a scam, it is unlikely that you will be able to recover your loss. The ACCC publishes this website to help consumers recognise and prevent scams.

For more information on how to protect yourself and your loved ones against scammers or to report a scam, please visit www.scamwatch.gov.au

The Terminology by Trish Dainton

Trish Dainton has published a book of poetry and prose to raise awareness and funds for those caring for people suffering with Huntington's Disease. Trish, who is from Greenwich, UK and sadly lost her husband to HD recently, has been exhibiting a poem from her book - Curse in Verse and Much More Worse (The Musings of an 'Unemployed' Carer).

Trish says, "My poem, 'The Terminology' is about the use of medical terms when referring to symptoms of the disease. Shortly after my husband was diagnosed we were sent a copy of a letter to his doctor which was written by his Neurologist. It contained the word 'anhedonia'. I had to look the word up and it made sad reading as it brought it home to me that, whilst my husband was still showing signs of recognising 'pleasure', it could be that he would lose even that most basic form of human awareness. Because of the complexity of the disease the chances are that many will come across words used in the description of symptoms that are not easily recognised. The majority of the terms given below were used in connection with my husband. I personally found it useful to look into the meanings of the words to try helping me get a handle on where those making assumptions about my husband were coming from."

"It's all Greek to me!" Is the phrase in my head,
As the words on the paper begin to be read.
Is it Greek, is it Latin? I haven't a clue,
But it sounds quite impressive how they describe you.

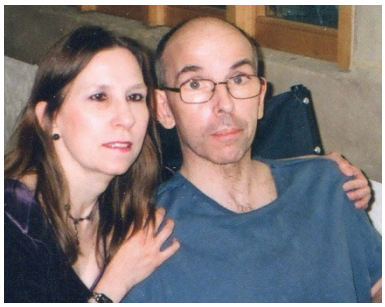
So I turn on computer and search on a word,
Oh why is the spelling of these so absurd?
And then one by one, as their meanings unfold,
It's no wonder they use them, the sadness they hold.

'Aspiration' tells me though happy you're fed,
The nutrition is aiming for your lungs instead.
'Dysphagia' tells me the food that I give,
Is making you choke more than helping you live.

'Dysarthria' tells me your mouth will not say,
What you want me to do, do you want it this way?
'Bruxism' tells me your teeth will grind more,
And whilst you do not notice, my nerves can't ignore.
'Ataxia' tells me your order is altered,
Explaining the speech and the steps that are faltered.
'Dystonia' tells I straighten in vain,
The stiff limbs contorting, contracting again.

'Alexithymia' tells me your feelings are dead,
Or you cannot express them as words can't be said.
'Anhedonia' tells me you cannot feel pleasure,
Devoid of the feelings you once used to treasure.

'Myoclonus' tells me the thrashing in bed,
And the knee in my back, and the punch in the head,
It's not that you mean it, it's not aimed at me,
There's a name for this symptom within your HD.



Trish Dainton with her late husband, Steve

THE HUNTINGTON'S DISEASE PROJECT – A Documentary

WeHaveAFace.org is the first organization founded to increase international awareness of Huntington's Disease through a cinematic form. The Documentary: *"The Faces of Huntington's Disease: I am No Longer a Faceless Face"* focuses on the personal stories of the International Huntington's Disease Community, and incorporates education from Medical Professionals within its content. The aim of The Huntington's Disease Project is to produce an independent, full-length documentary with individuals from all parts of the world. The film is the first of its kind, created by individuals within the JHD/HD community, and a legacy for future generations.

The Huntington's Disease Project is comprised of an incredible team of individuals within the Huntington's Disease community. We are found in many different parts of the world - from California - to New York - to the UK. The Film Team has joined efforts to create the Documentary, and to continue to provide valuable support to others within the JHD/HD community. Advocacy for Huntington's Disease is a key part of our daily lives.

Please visit www.WeHaveAFace.org and become part of this International effort! Please email us directly at WeHaveAFace@aol.com with any questions. To view the trailer, please visit- http://vimeo.com/25568188

James Valvano, Writer/Director

TOOLS FOR DISCOVERY OFFER POTENTIAL HOPE FOR HUNTINGTON'S

*The US Dept of Energy/Office of Science report on the "**Structural Formation of Huntingtin Exon 1 Aggregates Probed by Small-Angle Neutron Scattering**" study http://www.cell.com/biophysj/abstract/S0006-3495(11)00465-6 that was published 5-18-2011 - see Eureka Alert http://www.eurekalert.org/pub_releases/2011-05/drnl-npf051811.php*

http://blog.energy.gov/blog/2011/05/25/tools-discovery-offer-potential-hope-huntington%E2%80%99s

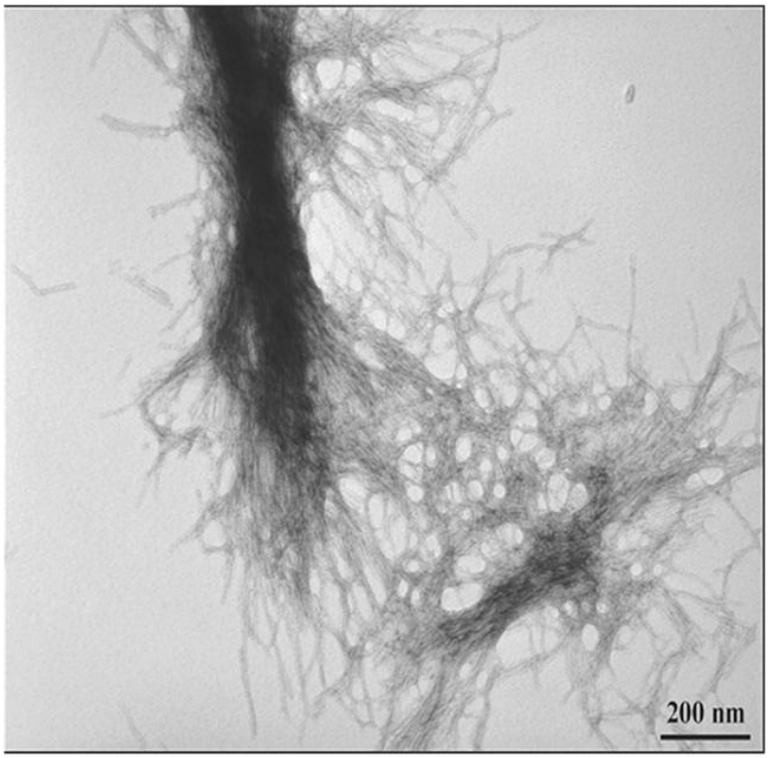
Submitted by Charles Rousseaux on May 25, 2011 - 3:24pm

Sometimes the right tool can shape the world…..or even better, touch a life.

That's true for researchers at the Department of Energy's Oak Ridge National Laboratory (ORNL) and the University of Tennessee, who recently used one of their tools to discover new truths about Huntington's Disease.

Huntington's Disease is an inherited disorder of body and mind. It begins with a single errant gene, which causes a single misshapen protein (huntingtin), which leads to a devastating series of consequences. Some 1 in 10,000 Americans are affected by Huntington's, which causes involuntary movements, losses of emotion, dementia and other significant brain impairments. While there are a few treatments, there is no cure.

Everyone carries the huntingtin protein. Scientists aren't exactly sure what it does, but they believe it plays a role in nerve cells (neurons) in the brain, and know it is critical for life. They also know that misshapen huntingtin proteins pile up inside neurons as the disease progresses, in thin deposits known as fibrils, and believe that the earliest aggregates may be the most toxic.

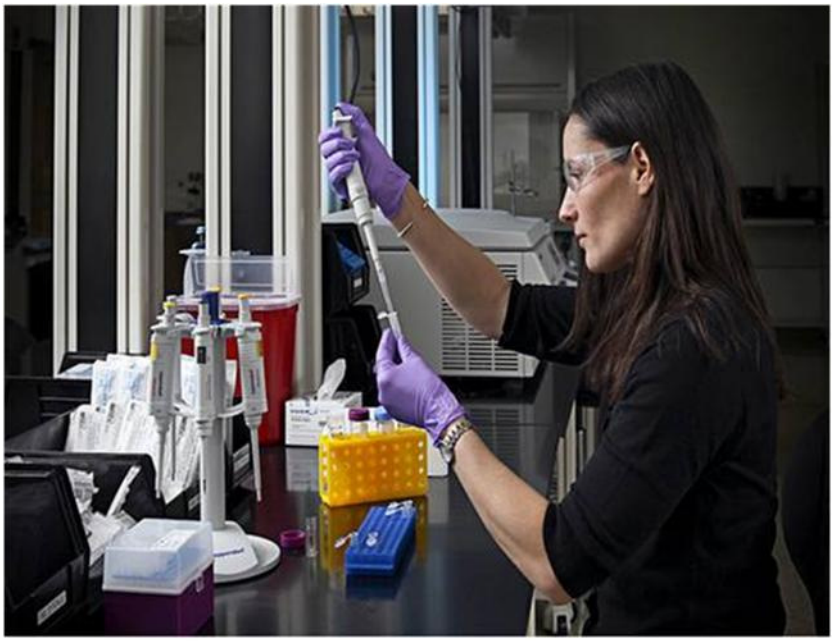


Transmission electron microscopy demonstrates the fibrillar nature of huntingtin aggregates. Courtesy of ORNL.

So researchers at ORNL took a look at the misshapen form of huntingtin aggregates in the earliest stages of disease at the smallest scale so far resolved, the sub-nanoscale level, tenths-of-billionths of a meter. By comparison, a sheet of newspaper is about 100,000 nanometers thick, and a human hair is approximately 80,000 nanometers wide. They used a tool called "Bio-SANS" (Biological Small-Angle Neutron Scattering Instrument), at ORNL's High Flux Isotope Reactor (HFIR). Bio-SANS – the cornerstone of ORNL's Center for Structural Molecular Biology – uses neutrons (tiny electrically neutral particles), to study the structure of larger, biologically-important structures like proteins.

This approach has advantages that lead to advances. Using Bio-SANS, researchers can 'see' how biological structures look in solutions, their natural state. The tool can also pinpoint the placement of small atoms in great detail, which allows scientists to understand how those structures change over time..

Atomic architecture matters. And through Bio-SANS, ORNL scientists were able to see and study the entire growth curve of the misshapen huntingtin proteins: How their individual components came together, how their toxic aggregates formed, and joined together into fibrils inside the neuron. (Read more about their results in Biophysical Journal.)



Flora Meilleur prepares protein solutions for structural investigation with neutrons. Courtesy of ORNL Flickr / Jason Richards.

Knowing the shifting shapes of those noxious structures may allow scientists to devise medicines that prevent them from forming, or counteract their toxic properties. ORNL's tools are leading to better targets, and perhaps potential treatments. It's a real return to the taxpayer.

But the full benefit of the tools ORNL scientists are using to study Huntington's, and other diseases like Alzheimer's and Parkinson's, goes far beyond a better balance sheet or a publication in a prestigious scientific journal. It's the prospect that they'll contribute to a treatment, or perhaps even a remedy.

This research was supported by the National Institutes of Health. HFIR and Bio-SANS are supported by the Office of Science. For more information on the DOE Office of Science, please go to: http://www.science.energy.gov/.

Charles Rousseaux is a Senior Writer in the Office of Science, US Department of Energy.

…these findings are encouraging

Research offers clue to halt Huntington's Disease

Reprinted courtesy of QBI Neuroscience News Issue 17 Autumn 2011

Surprising findings from a study into the brains of transgenic mice carrying the Huntington's Disease mutation could pave the way for treatments which delay the onset and progression of this devastating genetic disease.

Researchers at QBI have found that the brains of mice with Huntington's Disease nevertheless retain populations of the precursor and stem cells which can give rise to new neurons.

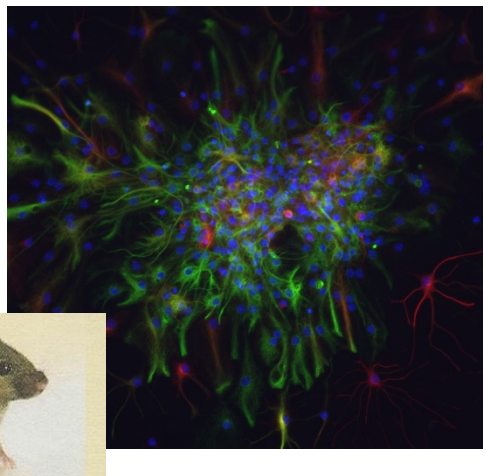
The potential for stimulating the production of new neurons in HD patients thus remained high, according to Dr Tara Walker, the postdoctoral fellow who carried out the work in the laboratory of Professor Perry Bartlett.

"Combined with previous findings which show that environmental enrichment and anti-depressant treatment delay both the onset and progression of HD in mice, these findings are encouraging," she says.

HD is a neurodegenerative disorder that results in progressive motor, cognitive and psychiatric deficits which eventually lead to death. Currently, there is no known cure.

However, the research, recently published in PLoS One (Walker et al, PLoS one 6: e 18153), holds out hope that retained cell populations in the brains of HD patients could one day be manipulated to replace degenerating neurons.

"This may not only allow the restoration of neurogenesis, but may also allow this process to be harnessed to repair other areas of neuronal cell loss."



Above: example of transgenic mouse. Right: A stem cell-derived neurosphere showing astrocytes (green) and a small number of neurons (red). Image Tara Walker.

Caffeine, Cannabis and Caution

Does caffeine accelerate Huntington's Disease? Does cannabis slow it down? HDBuzz looks behind the headlines

By Dr Ed Wild on July 06, 2011 Edited by Dr Jeff Carroll

Recent news stories suggest that Caffeine might be harmful to people with the Huntington's Disease mutation, while others claim that Cannabis might be helpful. Here's the lowdown on the science behind these stories, and why we think that a third 'C' - Caution - might be the best medicine when it comes to news stories about HD 'breakthroughs'.

Caffeine makes Huntington's symptoms start earlier?

High caffeine intake was linked with early symptom onset - but the study was small and relied on memory - and the link could go either way. The claim that *caffeine* may accelerate the onset of Huntington's Disease came from a presentation by Dr Pierre Krystkowiak, of CHU Amiens, France, to the International Congress of Parkinson's Disease and Movement Disorders in Toronto, Canada.

Krystkowiak's team studied 80 French patients with Huntington's Disease. Each patient completed a questionnaire about the amount of *caffeine*-containing drinks, like tea, coffee and cola, they'd consumed over the previous ten years.

Using the questionnaire results, they divided the patients into two categories — high and low *caffeine* intake. Then they looked at how old the patients had been, when they were first diagnosed with symptoms of Huntington's Disease.

Looking at the onset of symptoms in this way is difficult. HD is caused by a repeated "stutter" of three letters in the DNA code of the huntingtin gene (C-A-G-C-A-G…). People have different numbers of repeats and, on average, more repeats cause earlier onset of symptoms. The fact that HD patients have a range of repeat lengths makes studying variations in their onset tricky.

With this in mind, Krystkowiak's team found that, on average, the patients with a 'high' *caffeine* intake had developed symptoms about four years earlier than those with a 'low' intake.

In his presentation, Krystkowiak went on to explain that *caffeine* blocks communication molecules in the brain called '*A2A receptors*'. Those receptors are most prominent on the brain cells that die early on in Huntington's Disease.

So, people who drank lots of *caffeine* had earlier onset — and the receptors that *caffeine* blocks are prominent in HD-damaged brain regions… Surely this is a smoking gun (or possibly a steaming cup)? Shouldn't people at risk of HD should stop drinking *caffeine* straight away?

Hold your horses...

Look behind the headlines, check the facts, and don't make lifestyle decisions based on a single source of information. As anyone living with Huntington's Disease knows, making decisions about things like diet and lifestyle is never straightforward. Let's look beneath the lid of this study to see what's brewing beneath.

As Krystkowiak himself points out, *caffeine* intake has previously been shown, in much larger samples of patients, to be linked with **reduced** risk of Alzheimer's disease and Parkinson's disease — sort of the **opposite** of what was suggested by the Huntington's Disease study.

We know that Huntington's, Alzheimer's and Parkinson's share many features in common. So it would be a big surprise if something that makes one disease worse, actually protects against the other two. It's not impossible, but to buck a trend like that demands pretty strong proof.

So how strong is the proof in this study?

Well, the simple answer is we don't know — because the study hasn't actually been published yet.

That might sound like an odd thing to say about a study that has generated news stories and blog postings all over the web — but it's true.

The research was 'presented' to scientists at a conference in the form of a poster — but crucially, it hasn't been published in a **peer-reviewed scientific journal**.

Why does that matter? Well, peer review is the process where scientists show all their data to other experts, who check the results and statistics, and make sure that the conclusions drawn are supported by the data. Anything published in a reputable scientific journal has to go through the peer-review process, and publication makes all the relevant data available for readers to examine.

Presenting findings at a scientific conference is often a first step on the road to publication, and there are checks in place to make sure that what's presented isn't misleading. But the checks are much less rigorous than when work is submitted to a peer-reviewed scientific journal.

Is the research wrong?

Two chemicals found in cannabis were tested together in mice that had been 'poisoned' to show some features of HD.

We're not saying the research is wrong — it was done by reputable scientists, and there's no reason to doubt the results were as they've been reported. But exploratory research like this often gets blown out of proportion when it's reported in the news.

Journalists and bloggers need to make stories 'sexy' so that people will read what's written. That's easier with attention-grabbing headlines like 'Coffee accelerates Huntington's Disease', even when those headlines go much further than the science allows. The problem is worse when journalists have to write a story based on the small amount of information contained in a poster, rather than having a full peer-reviewed article to study and write about.

Why not give up coffee just in case?

On the basis of the evidence so far, we don't think there's enough proof that coffee is harmful — or beneficial, for that matter — to make a recommendation either way. If strong evidence is produced, we'll let you know. But meanwhile, here are a few reasons why we don't think this particular report should have HD family members flinging away their frappuccinos.

Firstly, the study was done in a small number of patients. That always makes findings less reliable than when large numbers are involved.

Secondly, the questionnaire about *caffeine* intake was 'retrospective' — it asked about *caffeine* intake over the **past** ten years. We know Huntington's Disease can affect concentration and memory, so people who developed HD symptoms earlier may have been less reliable in remembering how much *caffeine* they'd consumed. That could create a false impression that those with earlier onset had consumed more *caffeine*.

Thirdly, there might really be a link between coffee and the onset of Huntington's Disease — but it could actually be the other way round. Rather than coffee accelerating onset of HD, it could be that people destined to get HD early are more likely to be keen on coffee. We know that people with HD often become keen on particular habits and routines, so that's certainly possible. The presence of a link doesn't necessarily mean that *caffeine* accelerates the disease.

What about cannabis?

The news stories about cannabis being '*neuroprotective*' (protecting brain cells) in Huntington's Disease come from research led by Dr Javier Fernandez-Ruiz, and published in the Journal of Neuroscience Research. That's a peer-reviewed scientific journal, which is a good start. But again, news stories about the research have taken the published findings a bit far. It's important to look behind the headlines to see exactly what has been shown.

Learn more - go to http://en.hdbuzz.net/37 for dot points below:

- Blog posting about Krystkowiak's caffeine research in HD
- Journal of Neuroscience Research article on cannabis-based drugs in mice (full article requires payment or subscription)
- Improving Huntington's Disease clinical trial recruitment through patient and family education
- Interview: Graeme Bilbe, Global Head for Neuroscience at Novartis
- Interview: CHDI Management
- CHDI Report: Day 3

The researchers studied the effects of two chemicals, called THC and CBD, found in cannabis. They're also in the drug Sativex, which is used to treat symptoms of muscle stiffness in *multiple sclerosis*.

They didn't study the chemicals in human HD patients — the research was done in mice. And the mice they used didn't carry the genetic mutation that causes HD — instead they were normal mice that had been treated with chemical poisons that damage the brain. That damage is similar to what's seen in Huntington's Disease brains, but it's not quite 'mouse HD'.

The two chemicals had each previously been tested separately in rodents, and found to protect against some of the damage caused by the chemical poisons. The new study involved testing them together and trying to figure out how they worked. As expected, the two-drug cocktail did prevent some damage caused by the poisons, probably through a combination of antioxidant and anti-inflammatory effects.

So while this is interesting research, it didn't involve human patients, or any animals with the mutant HD gene, or any reefers, joints, spliffs or indeed hash-brownies whatsoever! It doesn't provide evidence that smoking cannabis is helpful or harmful for people with the Huntington's Disease mutation. For the time being, that's another decision where science can't yet give a clear answer.

On caution

We hope this article isn't too much of a downer. Everyone — including your HDBuzz writers and editors — gets excited by headlines about preventing the harm caused by the HD mutation. Excitement about science is good, because hope is more powerful when it's based on solid facts. Our advice is to embrace that excitement, but proceed with caution. Look behind the headlines, check the facts and, when it comes to lifestyle choices, 'all things in moderation' is pretty good advice, at least until strong evidence comes along either way. Finally, don't make lifestyle decisions based on a single source of information, including this one!

DO YOU KNOW WILLIAM O'CONNOR?

This is a request from Marie Shaw, UK, who is trying to track her Uncle.

Hello, I am a member of the HD support group in Liverpool UK. HD is very predominant in my family; the offending gene is from my father's side. My reason for getting in touch is that my father's brother (William O'Connor) moved to Australia around 1928 and from all accounts started a new life in Sydney, in Palmer Street at Woolloomooloo. None of his siblings knew of his whereabouts after that. I know that he was the eldest of nine children and was born in 1901 or 1902, so I could possibly have first or second cousins suffering from HD (if their father was unlucky enough to have the gene) who do not know their family history, and would like to know. My age is 71 so I imagine if I do have Australian cousins they could be a few years older than me possibly with children of their own. I am wondering if there is anyone in Australia trying, like myself, to fill a gap in their family tree. My uncle may have, for some reason, changed his name or had an alias. I would be very much obliged if you could help, as I have tried every other way I know to find anything about him.

If you have any information, please email me at walter.shaw@sky.com

Thank you, Marie Shaw

FINANCIAL ASSISTANCE TO HUNTINGTONS QUEENSLAND

We have received and gratefully acknowledge major financial assistance from the following donors:

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CAN YOU HELP US REDUCE OUR RUNNING COSTS?

At Huntingtons Queensland we are constantly seeking ways to keep our costs down so that we can put more money into providing assistance to our families. You can help us by opting to receive your Huntington's Newsletter by email rather than by post.

If you wish to help us, please send an email to admin@huntingtonsqld.com with your name and contact details. If you are a health professional, please include the name of your organisation.

Alternatively, please let us know if you DO NOT wish to receive our Newsletter, by EMAIL OR POST.

We also look forward to our members renewing their annual memberships for 2011-2012 and we welcome new members.

HUNTINGTONS QUEENSLAND

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Huntingtons Queensland
is a not-for-profit service organisation.
Established in 1976.

Our Mission is:

To provide professional support and advocacy for all persons affected by Huntington's Disease in Queensland.

Our Services Include:

- Providing individual and family support
- Facilitating the HD Day Respite Program
- Facilitating support group meetings
- Recreational activities for families with young children
- Organising respite holidays
- Providing information to families and health professionals
- Distributing a regular Newsletter
- Co-ordinating the annual HD Awareness activities
- Fundraising activities

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Please feel free to submit articles or photographs for selection for publication in this Newsletter. The deadline for the next issue is 30th September 2011. Please email or post articles, details above. Please be aware that the Newsletter is published on *www.huntingtonsqld.com* in addition to postal and email distribution.